

## Data Sharing Agreement (DSA) Policy #AD 01-16-001

### **Purpose**

The purpose of this policy is to outline the procedures for the review and approval of applications submitted to the Iowa Department of Public Health (IDPH) for access to confidential Department data for use in public health practice or surveillance, or other statistical or verification purposes as allowed by statute or Administrative Code.

### **Definitions**

**Confidential Public Health Information, Record, or Data:** A record, certificate, report, data, dataset, or information which is confidential under federal or state law. As a general rule, public health records which contain personally identifiable information of a health-related nature are confidential under Iowa Law. More information about confidential public health records can be found in **IDPH Policy #ES 01-16-002, Disclosure of Confidential Public Health Information, Records, or Data.**

**Data Sharing Agreement (DSA):** A legal contract between IDPH and any external entity (including other departments within state government and Regent's institutions), or between two internal IDPH programs in which parties agree to the exchange of specified variables within an IDPH dataset, or in some cases paper files, at identified intervals of time, and use of the data does not meet the definition of research constituting a need for a Research Agreement.

**Data Owner:** The IDPH employee who is in the position that is responsible for the dataset, as designated by the director or director's designee or as indicated by statute. The data owner may authorize or deny access to certain data within IDPH commensurate with procedures described below, and is responsible for accuracy and integrity of the data and timely response to data inquiries.

**Data Custodian:** The IDPH employee who is in the position responsible for the safe custody, transport, and storage of the data. The data custodian is also responsible for the technical environment and database structure that hosts data. The custodian for IDPH data may be indicated by statute (e.g., State Registrar of Vital Records); however, the physical custodian for the majority of IDPH data is the Bureau of Information Management and Bureau of Health Statistics.

**Data Steward:** The IDPH employee who is in the position responsible for data content, context, and associated rules for interpretation of each data source. The data steward(s) serves as an intermediary between the data owner and data custodian. Data stewards have the responsibility of ensuring that the appropriate steps are taken to protect the data and that respective policies and guidelines are being properly implemented. The data owner and steward might be the same person.

**Implied Confidential Public Health Data:** Data which can be used to indirectly establish the identity of a person named in a confidential public health record by the linking of the released information or data with external information which allows for the identification of such person. More information about implied confidential public health data can be found in **IDPH Policy #ES 01-16-002, Disclosure of Confidential Public Health Information, Records, or Data.**

**Personal Gain:** Efforts by any employee that benefit an IDPH employee personally or professionally and where the "effort" is outside of the scope of normal job duties. Examples of efforts qualifying as "personal gain" include, but are not limited to: using IDPH data for a

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dissertation or other graduate work, using IDPH data in consulting work or in other supplemental employment.

**Requestor:** The individual requesting and using the data. The requestor is responsible for the management of the DSA. The requestor is the point of contact for all communication with IDPH related to the review of the application and is also responsible for non-IDPH individuals who are authorized to access data received through the DSA.

**Research:** A systematic investigation designed primarily to develop or contribute to scientific, medical, public health or psychosocial disciplines and generalized knowledge and not for personal gain. Examples of “research” are included in **Appendix A of IDPH Policy #AD 07-12-004, Research Agreement and Research and Ethics Review Committee.**

**Research Agreement:** A contract between IDPH and any external entity (including other departments within state government and Regent’s institutions) in which IDPH agrees to release specific variables within a dataset that includes parameters of time and geography as requested in a research application. A research agreement is required when the receiving entity intends to use the requested dataset for the purpose of research and is bound by the confidentiality requirements in the research agreement.

**Research and Ethics Review Committee (RERC):** The Research and Ethics Review Committee (RERC) is responsible for evaluating and approving or denying requests for IDPH-owned data for the purposes of research. More information about the RERC can be found in **IDPH Policy #AD 07-12-004, Research Agreement and Research and Ethics Review Committee.**

## **Policy**

Applications for access to confidential or implied confidential IDPH data requested for the purpose of public health practice or surveillance, or other statistical or verification purposes, must be reviewed and approved by the Data Management Program, the data owner, the director of the division where the data are owned or when appropriate the State Registrar of Vital Records, and the Assistant Attorney General assigned to IDPH.

This policy applies to all external requests for confidential or implied confidential data for non-research purposes, and all internal requests for confidential or implied confidential Vital Records, HIV, Substance Abuse, Traumatic Brain Injury, or Child Death Review data for non-research purposes. Internal requests for all other types of confidential data will be evaluated for the need for a DSA by the Data Management Program on a case by case basis.

**If confidential or implied confidential data will be shared as part of a contract or other agreement, the Data Sharing Terms (found in the special conditions template) and data sharing appendices, including variables, must be included as part of the contract.**

A fee may be assessed for the requested data. Refer to the **Fee Schedule for Vital Records Data** for more information about fees related to Vital Records.

**This policy does not apply to the review or approval of research applications in which research is the basis for the request. Research requests must be processed according to the procedures outlined in IDPH Policy #AD 07-12-004, Research Agreement and Research and Ethics Review Committee.**

**This policy does not apply to the review or approval of Open Records requests for public data. Open Records requests must be processed according to the procedures outlined in IDPH Policy #IM 11-04-015, Open Records.**

## Procedures

### External Requestors

All external entities (including other departments within state government and Regent's institutions) requesting access to confidential or implied confidential IDPH data must submit an application for data sharing, and a list of requested variables or data to the Data Management Program. This application is located at <http://idph.iowa.gov/PublicHealthData/data-requests>.

### Employee

IDPH employees receiving requests for confidential or implied confidential IDPH data from a person or entity **outside** of their IDPH program should refer this request to the Data Management Program. This includes requests from other internal programs or external sources. The Data Management Program, in consultation with the requestor and the data owner, will determine if the purpose of the request is for research **OR** for public health practice, surveillance, other statistical, or verification purposes.

### Employee Requests for Access to Data for Non-Research Purposes

IDPH employees requesting access to confidential IDPH data for surveillance, practice, or verification purposes that are owned by another IDPH program may be required to submit an application to the Data Management Program. This application is located at <http://idph.iowa.gov/PublicHealthData/data-requests>. Explanations are listed below:

- 1) *An IDPH employee **MUST** submit an application for access to IDPH data to the Data Management Program if:*
  - a. Data requested are confidential or implied confidential as defined in **IDPH Policy #ES 01-16-002, Disclosure of Confidential Public Health Information, Records, or Data.**
  - AND
  - b. Data requested are Vital Records, HIV, Substance Abuse, Traumatic Brain Injury, or Child Death Review data (these data have special statutory limitations to data sharing);
  - OR
  - c. Data requested are being shared with an outside person or entity for use in public health practice or surveillance or for other statistical or verification purposes, including for contribution to other datasets or publications;
  - OR
  - d. Data requested will be used outside the normal scope of job duties and for personal gain of any kind.
- 2) *An employee **MAY NEED TO** submit an application for access to IDPH data to the Data Management Program if:*
  - a. Data requested are confidential as defined in **IDPH Policy #ES 01-16-002, Disclosure of Confidential Public Health Information, Records, or Data.**
  - AND
  - b. Data requested are owned outside of the employee's program.

**The need for a DSA between internal programs for the exchange of data NOT related to Vital Records, HIV, Substance Abuse, Traumatic Brain Injury, or Child Death Review will be evaluated on a case by case basis.**

If data sharing is for a federal grant requirement, consult with the Data Management Program to ensure the protection of data is outlined adequately in the grant agreement. The Data Management Program is available to IDPH employees for consultation on release concerns and guidance as to the need for a DSA agreement.

Any data released to an external entity whether or not it has been approved via this process must follow **IDPH Policy #ES 01-16-002, Disclosure of Confidential Public Health Information, Records, or Data.**

### **Application Requirements for IDPH DSAs**

**All NEW applications submitted to the Data Management Program for consideration must include the following documents:**

- Application for DSA (located at <http://idph.iowa.gov/PublicHealthData/data-requests>)
- List of requested variables or files (variable lists are available upon request from the Data Management Program)
- Any additional documentation requested by the Data Management Program

**All applications submitted to the Data Management Program for consideration for CONTINUATION must include the following documents:**

- Current DSA #, date current agreement was effective, and a description of any changes in data usage
- Updated continuation application for DSA
- List of requested variables or files
- Any additional documentation requested by the Data Management Program

The Data Management Program reserves the right to request additional documentation outside of the parameters listed in the policy.

Consultation with the Data Management Program and/or data owner prior to submission of application may be appropriate under certain circumstances. The Data Management Program is available for consultation on release concerns and guidance when an application is needed or not necessary.

### **Data Management Program**

The Data Management Program within the Bureau of Planning Services is responsible for receiving and processing all applications for non-research-related DSAs and requests for confidential IDPH data. This includes applications from IDPH staff members and external entities. The following sections detail the procedure for processing DSA applications and requests.

All applications will be placed in queue for review upon receipt of application from requestor. After receipt of the complete application, the documents will be reviewed and a response provided to the requestor typically within one month, but no more than three. The timing of reviews and final decisions is dependent on completeness of the application, requestor responsiveness to comments or questions from the Data Management Program, and the number of applications under review at that time.

When an application is received, the Data Management Program will meet with the data owner and the bureau chief of the bureau in which the data are owned to review and consider the request. The Data Management Program will consult with other individuals when appropriate.

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Upon data owner's approval of the request, a DSA will be drafted. The draft will be reviewed by the Assistant Attorney General assigned to IDPH to assess the legal authority governing the release of the requested data. The division director, or when applicable, the State Registrar of Vital Records, will then review and act as the signatory on the agreement.

Responsibility for fulfilling the approved data requests is that of the data owner and custodian. The data owner and data custodian will receive approval in the form of a copy of the DSA from the Data Management Program. If there is not a data owner or custodian identified for a dataset, the Data Management Program will identify the appropriate contact to fulfill the request.

### **Data Owner and Bureau Chief**

The data owner and bureau chief are responsible for review and consideration of the data request. This review and consideration will be based on an evaluation of the requestor's need for confidential public health records and the benefit of this data sharing. The data owner and bureau chief will make a recommendation to the division director to approve or deny the request. All Vital Records requests will be evaluated by the State Registrar of Vital Records.

**If confidential or implied confidential data will be shared as part of a contract or other agreement, the data owner must include the standard data sharing terms and data sharing appendix, including variables.**

### **Division Director**

The division director provides administrative oversight to assure the intended agreement fulfills the IDPH mission and public health scope and strategic plans. The division director, or when applicable the State Registrar of Vital Records, will sign the agreement for IDPH.

The division director and the State Registrar of Vital Records are the only persons authorized to obligate IDPH data through approval and execution of a DSA.

### **Expiration of DSA**

The term of the DSA is a maximum of five years from the starting effective date, unless terminated early in accordance with the DSA. If the requestor anticipates their data needs continuing past the expiration date, they must resubmit an application for continuation of the agreement at least 60 days prior to the expiration date of the agreement so that there is no lapse.

At the final expiration of the agreement the requestor must destroy the data in a way that renders the data unidentifiable and useless. In addition, the *Confirmation of Destruction* form must be completed and returned to the Data Management Program upon completion of the project. This must be done within 60 days of the expiration date of the agreement or completion of the project, whichever occurs soonest, unless an application for continuation has been submitted.

### **Policy/Procedure Violations**

**For IDPH employees** - violations of the policy are grounds for disciplinary action, up to and including discharge.

**For all persons and entities participating in a DSA with IDPH** – IDPH has the authority to employ penalties for misuse of data. Penalties for violations of the DSA may include, but are not limited to:

- Revocation of the DSA and notice to the immediate supervisor of the violating party.
- Notice of revocation of the DSA to the entity's director.
- Immediate destruction of data confirmed by independent third party, and may need to be verified by IDPH.
- Restitution of funds to the grantor agency as appropriate

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- Removal of the violating party from the particular project, or special monitoring of future work
- Letter of reprimand, probation, suspension, salary reduction, rank reduction or termination of employment for the violating party
- Withdrawal or correction of all pending or published documents emanating from the research where the misconduct was found
- Future requests by the violating requestor and other implicated parties may be denied.
- Other sanctions as authorized by federal or state law.

The signatory is responsible for all violations of the DSA, including anyone under their authority with access to confidential or implied confidential data shared through the DSA.